CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

October 7, 2014

The Honorable Harry Reid
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, DC 20510

Dear Majority Leader Reid and Minority Leader McConnell,

On behalf of the Cystic Fibrosis Foundation, representing 30,000 people with cystic fibrosis (CF) in the United States, I write to express strong support for the Newborn Screening Saves Lives Reauthorization Act, HR 1281, and request swift action on this important legislation prior to the adjournment of the 113th Congress.

Cystic fibrosis, one of the most common life-threatening genetic diseases, is primarily a lung disease that makes the body produce thick, sticky mucus that clogs the lungs and leads to life-threatening infections and serious digestive complications. In the 1950s, those with CF rarely lived to attend elementary school. Now, thanks to advances in the development of treatments and access to specialized, quality care, those with cystic fibrosis are living into their 30s, 40s, and beyond.

The Newborn Screening Saves Lives Reauthorization Act will renew federal programs that provide support and guidance for state efforts to ensure that every newborn is tested for at least 31 conditions present at birth which, if undetected and untreated, can lead to serious disability or death. Newborn screening can help infants who are affected by CF begin treatments earlier, which can help them grow and develop more normally and minimize or delay complications. Before newborn screening, most people with cystic fibrosis were diagnosed when symptoms of the disease caused health problems. Now, an infant diagnosed soon after birth will have the advantages of starting life healthy and receiving early, specialized treatments that were not available even a decade ago.

There can be serious consequences for failing to detect CF in newborns. For example, there is convincing evidence from research in Colorado, Wisconsin and London that malnutrition due to pancreatic insufficiency and intestinal malabsorption occurs in many CF infants by

two weeks of age. Nutrient deficiencies may include essential fatty acids and vitamin E that are important in brain growth and development.

Moreover, as we have entered a new era in which the basic defect in some with CF can be treated with innovative new CFTR modulator therapies, expediting the diagnosis of CF has become a crucial goal. For example, if these therapies are started early enough in patients who are otherwise destined to have pancreatic insufficiency, pancreatic function could be preserved. Similarly, the prevention of CF lung disease will require the combination of very early diagnosis of CF and early therapy with CFTR modulators as lung disease also begins very early. The timely detection of CF through newborn screening has never been more important.

Once again, we urge swift action on the Newborn Screening Saves Lives Reauthorization Act and greatly appreciate your attention to this critical issue. We look forward to working with you as we continue our mission to find a cure and control for this life-threatening disease, and as we continue to build hope and add tomorrows every day for those with CF.

Sincerely,

Robert J. Beall, Ph.D.
President and Chief Executive Officer